

Lessons from lockdown: Autistic students, parents and mainstream schools

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Funding information

British Educational Research Association

Abstract

This paper reports on the findings of a BERA-funded small-scale project that explores the impacts of COVID-19 lockdowns on the educational experiences of autistic children and young people who attend mainstream schools and their parents/carers in England. We observe that, unsurprisingly, lockdown resulted in associated stresses for families. However, our main argument is that for the participants, the pandemic has not been experienced to the same extent as is popularly understood; that is, causing major disruption to children's schooling experiences and/or unusual levels of social isolation. Using the concept of stigma as a theoretical resource, we argue that this is because the families with whom we spoke were *already* experiencing, pre-COVID-19, disrupted schooling and degrees of social isolation. Indeed, for many of the young people, the break from school occasioned by lockdown allowed them a release from the more negative and stigmatising aspects of their routine experiences within school. We therefore argue that the disruption of the pandemic sheds light on how stigma shapes students' daily school experiences.

KEYWORDS

autism, mainstream schools, pandemic, stigma, families

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Key insights

What is the main issue that the paper addresses?

The paper addresses the experiences of families with autistic children in the first lockdown in England occasioned by the COVID-19 pandemic. It also discusses the children's experiences at school prior to the pandemic.

What are the main insights that the paper provides?

The paper's main insight is that whilst lockdown occasioned its own stresses for families, especially around home schooling, it also offered the young people a release from the often-stigmatising experiences of being an autistic student in mainstream schools.

INTRODUCTION

Epidemics, as periods of intense disruption, serve as 'mirrors held up to society in which more general patterns of social values and attitudes appear in sharp relief' (Rosenberg, 1988, p. 327), serving to highlight patterns of social inequality and marginalisation (Dingwall et al., 2013; Lupton, 2021). This paper develops our BERA report (Oliver et al., 2021) to analyse the experiences of COVID-19 lockdown for families with autistic children in mainstream schooling. We contribute to existing literature by arguing that the unprecedented nature of lockdown reveals much about the strain and stress inherent in attending mainstream schools for many of the young people. The demands of lockdown and home schooling were, for participant families, mitigated somewhat by a sense of relaxation and release from the standardised expectations of school, thereby questioning the extent to which mainstream schooling is experienced as inclusive by autistic young people.

We make this argument in relation to the experiences of the participant families, starting our discussion by introducing Autistic Spectrum Condition (ASC) and experiences of autistic students in existing educational provision. Second, we discuss sociological understandings of stigma and relate these to autism, as they offer useful theoretical concepts for our study. Next, after setting out our research design, we discuss our analysis, arguing that, despite the attendant pressures, lockdown offered many of the autistic participants a release from their experiences of misrecognition at school. We conclude that the pandemic—as a disruption of normality—throws an acute light on how 'hierarchical social relations' (Link & Phelan, 2014, p. 25) both create and sustain autistic children's liminal positioning in mainstream schools. As such, our aim is to understand how families of children and young people with autism experienced the unprecedented event of national lockdown and to consider what this reveals about families' lived experiences, not only of this time, but also during 'normal' times.

AUTISTIC CHILDREN AND MAINSTREAM SCHOOLING

In line with the social model of disability, we recognise that the construct of 'normal' is possible only if compared with a body deemed abnormal (Lester & Paulus, 2012, p. 261), and that the ability to define these is largely possessed by the able-bodied (Lester & Paulus, 2012, p. 261). However, challenges to understandings of autism as deficit, as impairment, and attempts to reframe it more positively as a 'neurodiverse identity' have gained much currency in the

last 20 years (Grinker, 2020). Nevertheless, for many on the spectrum, the experience of navigating social space remains a disabling one (Botha et al., 2022). Mainstream education settings rely on standardised procedures, and research suggests that they are not always fully sensitised or equipped to respond to the needs of autistic students (Brede et al., 2017; Hummerstone & Parsons, 2021; Lilley, 2013). Autistic children in mainstream provision are judged to be able to respond to the academic demands of mainstream schooling, but may find themselves marginalised and 'othered' by peers and teachers for behaviours understood as 'abnormal, for example, displaying intense interests (Humphrey & Lewis, 2008; Wood, 2021). They are also at risk of experiencing co-morbid mental health difficulties, including anxiety and sleep disturbance (Roberts & Webster, 2020; Simonoff et al., 2008).

One in 100 children in the United Kingdom currently have a diagnosis of autism (British Medical Association (BMA), 2019a, 2019b) and government statistics for 2020/21 show that numbers are increasing.¹ There is a rising demand for Education, Health and Care Plans (EHCPs) (DoE, 2021) which identify the support a child needs and commits local authorities to resourcing the provision. Existing delays to both diagnoses and provision of support have been identified (British Medical Association (BMA), 2019a, 2019b) and these have been intensified by the pandemic (Crane et al., 2019; Oakley et al., 2021).

AUTISM, STIGMA AND POWER

Post-structuralist accounts of autism emphasise the historical and social contingency of its previous and current manifestations. Mullen (2015, p. 5), for example, argues that 'autism appears through narratives, behaviours and social norms that are not reducible to some neurobiological condition alone', and of course social norms and assumptions change over time and space. Discussing contemporary American discourses about autism, McGuire (2015) identifies the language of a 'war on autism', noting that autism is commonly positioned as stigma:

though not necessarily guilty of taking life away per se, [it] is rather guilty of infiltrating it, destroying it, ruining it, spoiling it (Goffman, 1963). Autism is time and time again conceived of as nothing other than an undesirable, and even dangerous, individual biological pathology. (p. 359)

Dominant notions of autism as stigma are encapsulated in the idea of 'autism as an epidemic' (McGuire, 2015, p. 360), a 'broken self, psychically and biologically' (Sarrett, 2011, p. 152). Recently, such discourses—especially in the wake of identity politics and recognition of the social model of disability—are increasingly challenged from a neurodiversity perspective, and by the accounts of autistic young people and adults (Grinker, 2020; Leadbitter et al., 2021). Nevertheless, popular culture still contains 'reductive representations' of autistic people (Black et al., 2019, p. 31), and accounts drawing on the voices of well-known autistic people tend to focus more on *their* adaptive success, not that of wider society (Mullen, 2015).

Such representations still shape public understandings, especially as autistic children and young people may display behaviours—repetitive actions, highly focused interests and conversations, withdrawal and/or anxiety over routine changes—which challenge social norms (Roberts & Webster, 2020). These may be considered inappropriate or disruptive in a school context, thus becoming a source of stigma (Farrugia, 2009). Goffman's seminal work emphasised the relational aspect of stigma, arguing that we need to use 'the language of relationships' (Goffman, 1963/1990, p. 13; see also Scambler, 2018) to describe stigma, which is itself 'an undesired differentness from what we had anticipated' that results in a 'discredited identity' (Goffman, 1990, p. 15). Parents also have to manage 'courtesy stigma'

which describes people who are associated with stigmatised groups (Farrugia, 2009; Francis, 2012; Goffman, 1963; Gray, 2002) and results in both they and the child having to manage 'spoiled identities'.

Goffman (1990, p. 46) observes that families' effectiveness in throwing a 'protective capsule' around a child varies by social class, and it is when the child moves from the private sphere of the home to the public one of the school that this capsule is often challenged. Much research details how parents seek to manage the threat or actuality of stigma by, for example, calling on children's medical diagnoses 'to articulate an unspoiled subject position' (Davidson, 2021; Farrugia, 2009, p. 1024). Autistic individuals are also engaged in agentic strategies to manage stigma. Botha et al. (2022), for example, describe their participants as engaged in strategic disclosure of their autism and reframing it in their own terms. However, the sheer weight of stigma attached to autism can make challenge difficult, especially for young people (Han et al., 2022).

Within a contemporary rethinking of the sociology of stigma (Thomas, 2021), researchers have critiqued existing research as 'often side-lin[ing] questions about where stigma is produced, by whom and for what purposes' (Tyler & Slater, 2018, p. 721; see also Farrugia, 2009; Link & Phelan, 2014; Thomas, 2021; Tyler, 2020). Tyler further notes that much stigma research is 'motivated by a concern with changing attitudes and behaviours; through, for example, increasing people's "tolerance" for particular stigmatised conditions' (Tyler, 2020, p. 243), which 'leaves an unjust world intact' (Thomas, 2021, p. 452). Sociological accounts therefore argue for a focus on macro-level structures and forces in addition to the relational, interactional experience of stigma, as the former draws our attention to the way in which stigma operates 'as a classificatory form of power' (Tyler, 2020, p. 260), embedded within 'the social relations of capitalism' (Thomas, 2021, p. 453). Scambler (2018, p. 777) argues further that stigma has been 'weaponised' by a neoliberal emphasis on self-sufficiency and self-regulation, in 'a cultural intensification of individualism' which recasts stigma from shame into blame for deviance from the norm.

Such arguments demonstrate the way in which questions of stigma are always related to questions of power. Link and Phelan (2014) turn to Bourdieu's explanation of symbolic power to underpin their own concept of 'stigma-power' and highlight three ways in which power operates within stigma. First, cultural judgements of value and worth play out within processes of stigma. Hence with regard to autism, privileged parents can more easily than their disadvantaged counterparts, work to restore their children's 'spoiled' worth through recognition of their neurodiversity (Davidson, 2021). Second, those affected by these judgements often come to accept marginality in the social order, in a form of internalised self-stigma (see Botha et al., 2022 in relation to autism). Third—and most relevant here—is that symbolic power often plays out through taken-for-granted aspects of culture and is 'thereby hidden or "misrecognized" by both the people causing the harm and by those being harmed' (Link & Phelan, 2014, p. 25).

In the following analysis, we therefore draw attention to how stigma operates 'in hidden and indirect ways' (Link & Phelan, 2014, p. 25). In other words, discrimination is structural and indirect, in addition to being directly generated via interaction; it is also 'hidden' through institutional practices and 'hierarchical social relations' (Link & Phelan, 2014, p. 25). Mainstream schools are required to adjust for individual student needs, but also apply standardised procedures and regulations to manage large numbers of young people. Grinker (2020, p. 57) argues that stigma 'is deeply embedded in historically contingent structural conditions of modern capitalism and ideologies of individualism that shape ideals of the modern worker' and that, on these grounds, the requirements of autistic people may therefore be cast as 'unreasonable'. He cites an eighteenth-century doctor who describes mental illness as 'the "general inability to follow the rhythms of social life" (Chilcoat, 1998, p. 12)' (Grinker, 2020, p. 59). These observations are very relevant to understanding how autistic

young people can be marked out as failing, for simply being unable to follow the rhythms and requirements of standardised school life, an argument that arose from the narratives of the parents with whom we spoke and is explored in more detail below.

METHODOLOGY

The study is a small-scale one, responding to BERA's call for rapid-response research on the educational impact of the COVID-19 pandemic (Oliver et al., 2021). However, our participants' accounts focused on *pre*-pandemic life, as well as life during the first lockdown in 2020 and the initial return to school.

Our position as researchers responds to Mullen's (2015, p. 5) suggestion that 'we might... ask how society can speak in such a way that autism no longer appears as a disorder but as a constellation of different modes of cognition and socialization'. As such, we avoid 'deficit-based' narratives (Pavlopoulou et al., 2020; Todres et al., 2009) and draw on our disciplinary backgrounds in sociology and developmental psychology to question such assumptions. We also drew on the lived experience and expertise of one of the researchers as a parent to three autistic children, as well as parents in an advisory group (four mothers of autistic children) to develop our research instruments and discuss emerging themes. This group met twice during the project and its members were not among our interview respondents.

The research proceeded in two phases. In phase one we distributed a recruitment survey through online parent groups across different English regions, and via Twitter, to attract participants. Potential participants were asked to submit brief details including demographic information and details relating to their child's background, diagnosis and educational experiences. In a short turnaround of two weeks, we received 25 responses, and from these were able to secure 17 interviews with parents, with the majority having children over 10 years old. Respondents were provided with further written information, and semi-structured interviews (lasting 60–90 minutes) were recorded with consent on Zoom throughout December 2020. Our interview schedule was designed to encourage participants to share their family's lived experiences of pre-pandemic schooling, lockdown and the initial return to school in September 2020, and elicit how they assigned meaning to these experiences (Pavlopoulou & Dimitriou, 2019; Seidman, 2006). Parents and children were offered a £15 supermarket voucher as a token of appreciation, but this was not advertised beforehand. The parent sample is in Table 1.

It is important to note that, as defined by occupation, the sample was predominantly, but not wholly, middle class, and included a number of those who were active around and/or highly informed about autism, including a local councillor, five parents who had studied, researched or had professional experience of working with autistic children and one who was a freelance consultant and author on autism.² This was, then, an advantaged and informed group, who nevertheless still experienced stigma.

Parents were the primary focus of our research, as we wished to understand their involvement with education and schools during lockdown, and we recognised the importance of setting these within the context of their earlier experiences of navigating their children through the school system. However, we also wished to include the children's accounts of lockdown, and six children (all White British, 1 female, 5 male, 11–17 years old) chose to speak with us. This particular paper primarily reports parental perspectives, but we hope to focus more on autistic children's own accounts of their schooling in future work.

This study was conducted in accordance with BERA's (2018) ethical guidelines and was approved by UCL's Institute of Education Research Ethics Panel. We are acutely aware of the emotive nature of discussions of home and school life and the pandemic, and of the

TABLE 1 Participant characteristics.

Number	Gender	Location (English region)	Ethnicity	Number of children
17	15 female 2 male	7 London & SE 3 North West 2 North East 2 East of England 2 South West 1 West Midlands	10 White British (WB) 3 White Other (WO) 1 Black British (BB) 2 British South Asian 1 Latin American	23 school-aged autistic children (18m, 5f); 8 at primary, 15 at secondary school (all state schools)

anxiety and stress that may arise, so with all participants we sought to pause the interview—offering them a chance to discontinue if they showed signs of distress.

All three researchers were involved in hand-coding the data, using thematic analysis (Braun & Clarke, 2019) to chart regularities in the data in relation to particular themes, and identify both prevailing tendencies and discrepant cases (Lecompte et al., 1993). Initial theoretical categories were drawn from existing literature, research and theory on autism, SEN/D and schools and stigma, and were refined and challenged through further engagement with and scrutiny of data. We discussed our coding as a team, reviewing all scripts, to ensure that we had shared understandings of the process. Our preliminary analysis was shared with and informed by discussions with the parent advisory group.

We proceed through discussing families' experiences of schooling pre-pandemic and then consider their experiences of lockdown. We note that for all the families, difficult and negative interactions with schools dominated the narratives.³

ANALYSIS

Prior to the pandemic: Misrecognition and difficulties in adapting school practice

The participants' accounts of educational experiences pre-pandemic indicate that autistic young people and their families are vulnerable to stigma associated with autism, as neurodiversity appears little understood in many schools (also Farrugia, 2009; Francis, 2012; Gray, 1993; Lilley, 2013). In our research, this mis/lack of understanding of autism existed long before the pandemic and, according to these parents, took two main forms. The first was a discriminating assumption from some teachers that the children *chose* their behaviour; the second was the reluctance by some schools to adapt provision, seeing such requests as unreasonable (rather than lawful) and impossible within the 'normal' operation of the institution.

On the first point, some participants described how their children's acute anxiety—which made it intensely challenging for them to participate at school—was understood by some teachers as demonstrating the child's *choice* of non-compliance. Rachel commented regarding her daughter's school:

They don't seem to understand the difference between a child being wilful and a child being anxious. They claim to, but they just don't seem to get it [...] They sent [a message in the home-school contact book] the other day that was saying 'she CHOSE not to do the work' in, like, capital letters. (Rachel, White British, three autistic children aged 12, 9 and 6)

Similarly, some parents spoke of their children's meltdowns or refusals to conform being understood as poor behaviour and as reflecting poor parenting choices, emphasising their apparent failure in terms of individual responsibility. Nicole and her son, Tom, are Black British. Tom was the oldest child within the sample, and he had been through five different schools before finding an accessible education setting in a mainstream school with an autism provision. He then progressed successfully to his current sixth-form college. Here, Nicole reflects on Tom's experiences, arising from his positioning at the intersection of race and disability. She describes his struggles to claim a positive learner identity in the face of some teachers' negative attitudes, assumptions and misunderstandings of autism, and hers to maintain her credentials as a 'good' mother:

There was that mismatch [by his teachers] between thinking well, he's a bright child, there were no obvious developmental issues, [...] he's just being naughty. And clearly you're not parenting him correctly [...] There still wasn't a real understanding of what neurodiversity looked like [...] In the primary years, definitely there was a huge resistance to investigating what was causing his outbursts, huge resistance to making adaptations, and a huge sort of prejudice that I had somehow done something wrong and that I was the cause... you know I wasn't bringing him up properly. So, I was asked things like 'did he have breakfast this morning?' and you know 'what time does he go to bed?' [...] In a way his intellect worked against him, because there's an assumption that he can listen to instructions and behave. 'He's choosing not to use his red card', I was told. But when you're talking about kids with emotional dysregulation, they don't always have the time to understand that they're going to have a meltdown. But [his teachers] only perceived it in terms of his aggressive or defiant, you know lots of really negative language and I really had to fight to reframe it all [...]. (Nicole, Black British, son aged 17)

Nicole's narrative reveals again assumptions that autistic children are *choosing* behaviours that teachers find challenging and she argues that teachers are misrecognising the causes of those behaviours,. Those assumptions intensify when being Black is in the equation (Gillborn et al., 2012). Nicole continued:

*Black autistics and neurodiverse young people..., there is the invisibility of their neurodiversity and the hypervisibility of their race. So, it's the worst of both worlds.... He's so aware [now] that people perceive him as a young Black boy that he almost goes to the other end to not reach a stereotype. You know, he makes himself very quiet [...] and he really over-compensates... he keeps himself **very, very** contained. (Our emphasis)*

Nicole notes that her son knows people perceive him as a 'young Black boy' as if that in itself was a damaging stereotype. The only way he is able to 'pass' in a majority White world as both a Black and autistic young man is to work to remain 'very, very contained'. This exemplifies Link and Phelan's (2014) argument—used in relation to people with mental illnesses to avoid reminders of their 'less desirable' status—that stigma is a resource that keeps the stigmatised 'in', 'down' and/or 'away'.

Our second point is that we found that reactions to non-normative behaviour (particularly from those with invisible differences) are shaped by both hesitancy within some school environments to accept and appreciate difference and neurodiversity, and by the perceived cost to the school in terms of the time, money and energy of fully 'accommodating' autistic children. This articulates with the notion that there is an 'autism epidemic' overwhelming insti-

tutions and services with a rapid—and costly—spread of neurodivergence (Grinker, 2020). This perceived increased demand must be situated within the picture of the ‘broader political economy of neoliberal capitalist accumulation’ (Tyler & Slater, 2018, p. 732) as it manifests in contemporary English schools, steered by the demands of high-stakes testing, in a context of high teacher workload and, importantly, reduced funding, and one that relies on standardised assumptions and demands.

We suggest therefore that both responses—teachers' hesitancy to understand and appreciate neurodiversity, and an emphasis on its perceived cost to schools—explain the determination of some schools to stick to their existing procedures. Parents described how staff refused requests for relatively small changes to routine and regulations, such as meeting the child at the school gate to overcome anxiety about entering, or giving advance notice of changes in routine. James objected strongly to wearing his PE kit to school all day (a COVID precaution), but the school was initially unwilling to allow him to change directly before PE:

So that little kind of adjustment there where they're going to let James bring his PE kit [in to school, rather than wear it all day] and then he's going to be able to access [PE] [...] they're little things aren't they? But they're big things in our world. (Greg, White British, son aged 5) (see also MacLeod et al., 2018)

Olivia was due to start secondary school in September 2020. Her new school moved its transition activities online, without any adaptation for children with additional needs:

So there seems to be a systematic kind of lack of you know issues around inclusivity. Designing things for most children, but excluding some children just by default, just by poor design. (Samantha, White British, daughter aged 11)

At a pre-pandemic transition event for children with additional needs in the summer holidays, Charlie was too anxious to leave the car. His parents asked staff if they could come over to the car for a ‘chat’ but were told that there was not enough staff. In the context of reduced funding to schools, it may have been difficult to staff the transition event and still spare a teacher to safely leave and talk to Charlie. We cannot comment on whether this is at base a funding issue, or an attitudinal issue, and therefore to what degree this combines both interactional and structural stigma. Yet Charlie's example demonstrates the longer-term impacts of schools failing to make such adjustments, as he had an unsuccessful transition and only spent three weeks at his secondary school before being unable to attend further. His mother, Vicky, perceived that most of her requests for ‘personalised provision’ to prevent Charlie feeling ‘overwhelmed’, such as ‘somebody greeting him at the gate’ or having a small number of familiar teachers with whom he could interact in the inclusion room, were refused:

So, there was support there, but it was reliant on the child fitting in with the limited offering they could give. It wasn't about... ‘what's necessary for us to build a relationship, to create a sense of belonging and safety for this individual child?’ They just didn't have the capacity for that. And more troubling, I think they really didn't have the mindset for it either. (Vicky, White British, two autistic sons aged 15 and 12)

By refusing such changes to standardised practice, Charlie's school (to which he did not return) offers an illustration of the way in which ‘stigma processes serve the interests of stigmatizers in subtle ways that are difficult to recognize in the absence of conceptual tools that bring them to light’ (Link & Phelan, 2014, p. 24). Vicky understood the refusal to person-

alise school procedures for her son as due to a fixed mindset which simply saw Charlie as too needy, too demanding, too costly in terms of time and effort. Mullen's observations are relevant here:

This anxiety of integration enervates every institution touched by autism. The family, schools, hospitals and the state are all charged with the governance of autism – all are challenged to manage autism while causing a minimum of friction with existing institutions. (Mullen, 2015, p. 8)

This is not to say that there were not individual examples of inclusive practice. Trying to balance an individual student's needs with standardised school practices meant that particular staff members are often made responsible, or become informally so, for autistic students, while whole-school procedures continue unchanged. The participant parents appreciated the multiple demands on staff and the challenges posed to their capacity to respond, especially in a context of austerity—'an attempt to permanently disassemble the protection state' (Cooper & Whyte, 2017, p. 1; cited in Tyler, 2020, p. 249). Thus, one mother who described the Senco at her son's school as '*amazing*' notes that they have almost daily contact and, in some weeks, '*it could be 20 emails a week easily*' (Laura, White British, son aged 16). However, she recognised that if multiplied across other children with whom the Senco interacted, this results in a highly intensive workload.

The pandemic: A disruption of normality or familiar state?

In this section, we turn to families' experience of the pandemic and lockdown. Broader research draws attention to the pandemic's unequal impacts on differently positioned families, highlighting the acute struggles of disadvantaged families (e.g. Crenna-Jennings et al., 2021; Moss et al., 2020). For example, research by Twamley et al. (2023) into the effects of the pandemic on daily life highlights the 'COVID labour' that families carried out, in addition to the childcare and home schooling required during school closures. This labour includes the need for parents to review the safety of everyday tasks, and make decisions accordingly, and is stratified according to the resources people possess, thereby exacerbating existing inequalities of gender, ethnicity and class (Twamley et al., 2023). Our research indicates, however, that the participating families were already heavily involved in these forms of additional labour and had considerable experience of similar demands pre-pandemic: of managing schooling disruptions, adjusting to restricted and limiting conditions, feeling socially isolated and having to structure their day. This labour was a pre-existing and quotidian aspect of their lives, a point made explicitly by Vicky and several others:

We have a very structured life... like many families like ours, I can tell you what I'm doing in 46 Thursdays' time. There's no spontaneity... I've got friends who do not have autistic children, have perhaps more of what you might describe as a typical family life and they have been so badly affected by some aspects of the pandemic that have not bothered us. Because you know we have always been quite isolated, we have always had to think carefully about what we do and how we do it and where we go. (Vicky, White British, two autistic sons, aged 15 and 12)

Thus, what is particularly striking in our data is the extent to which the pandemic's hallmarks of disrupted schooling and social isolation were experienced as a *continuation* of an already stressful pre-pandemic pattern of life for families with autistic children who are already marked out as 'different' from others. The pandemic, Vicky argues, meant that others

now experienced something of their routine reality. The disrupted and fragmented access to full mainstream education caused by lockdown was already experienced by many of these children prior to the pandemic. Thus, in so-called 'normal' times, some of the children were on roll but, in practice, unable to attend and so were missing extensive periods of schooling (e.g. Vicky's son, Charlie, had been out of his mainstream school for over a year when we spoke with her). Some of the children had pre-existing and severe mental health challenges, including children who self-harmed, which meant attending school was often problematic. Others were being educated in school, but outside the classroom. For example, Beatriz (Latin American) reported that her son, Alejandro, spent most of Year 3 (aged 7/8 years) outside the classroom with a teaching assistant, due to his anxiety about being in a noisy classroom, with his school apparently content with this 'solution'.

For the general population, the work associated with the pandemic was additional 'COVID labour' arising due to the specific risks of the pandemic. For the participants, however, such labour forms long-term parental attempts to mitigate risks to their children's well-being, posed not by disease, but by a society that is apparently ill-equipped and ill-prepared to accommodate autistic children.

Lockdown as a release?

During lockdown, and to some extent in the initial return to school, the degree of stigma faced by the families eased considerably, as most of the children were at home. Thus, the lockdown occasioned 'staying in' and 'staying away' (Link & Phelan, 2014, p. 26). Of course, in this case, staying at home was enforced to try and control the pandemic. As a result, however, teachers were not required to engage with non-normative behaviours, while the young people were no longer subject to normative assumptions about how they 'should' respond (Skovlund, 2019) and were relieved from their positioning as challenging/problematic. Thus, the first lockdown was experienced (to varying degrees) as somewhat of a release from regular stresses of, as one mother said, '*always thinking the worst was going to happen* [at school]' (Helen, White British, son aged 16). Others explained:

I enjoyed it because I just enjoyed being able to stop. Life had been absolutely manic just before lockdown [...] I think we have probably seen too much of each other [now]... but we were doing jigsaw puzzles together, like that never happened [before]. (Claire, White British, son aged 10)

The family walks at 3 o'clock every day, I did really like that. (Louise, White British, son aged 9)

While this may be common to many families' experiences, the difference was especially striking for the autistic young people who welcomed staying in the safety of home under their family's 'protective capsule' (Goffman, 1990, p. 46). In contrast to the complexity of school demands, they experienced home as a place of security, simplicity and predictability. Olly (White British, 13 years old) commented: '*The really good thing about lockdown is that at least I feel comfortable, my family is safe and then I won't be too scared about the outside world... My parents, my favourite things I like to do [make me feel safe]*'. Gosia (White Other, with son aged 11) noted: '*When lockdown first happened, you could see this bliss on [son's] face*' and Grace (White British) described her son (aged 6) as becoming a '*free spirit*'. Likewise, Kayleigh commented that lockdown produced her son's '*preferred life... just us and a simple routine*' (British South Asian, son aged 4).

However, lockdown was also an ambivalent experience for both participant adults and children. Our sample was, as stated earlier, composed of families where at least one adult was employed and a majority in professional occupations. Within this relative security, the experience of lockdown for adults was shaped by a complex mixture of how the children adapted, the age and independence of the child, and the degree of social and economic resources available. This included the degree of input from school and other agencies, and the demands and security of their paid work, since at least one parent in our study faced the collapse of his arts-based industry, while another, Gosia, took on an expanded care role as her husband's mental health deteriorated. Lockdown was also further problematic for participant families, as it delayed diagnoses and the progression of therapeutic interventions (several parents mentioned that their children could not interact with these sessions when moved online). It also halted social groups and extra-curricular activities. As a result of families having reduced ability to access these vital professional and personal support systems, many were left emotionally exhausted by the end of lockdown (see also Tokatly-Latzer et al., 2021). Rachel spoke of 'dragging' herself through much of lockdown; Jaz, who was prescribed antidepressants, of 'pushing through'; and Lily commented that the sudden disappearance of support left them feeling isolated, and was 'really hard... challenging... but you just get on really, don't you? That's what you do'.

Home schooling was also a source of both labour and anxiety. Parents' pre-existing concerns about their child's educational progress meant that lockdown represented further upheaval to some of the children's already difficult educational trajectories, thereby provoking further anxiety and a heavy sense of responsibility. The amount of interaction with schools in term of work emailed home, and direct contact with teachers, varied greatly. However, all the parents noted that there was little or no adaptation to the materials provided by schools, to make them accessible for their children (Greenway & Eaton-Thomas, 2020). This meant that many quickly gave up on home schooling, at least in terms of following the school's materials. Grace, for example, described the learning materials sent to her son's Year 1 class as 'unfathomable'. Similarly, Donna described the demands she faced with home schooling:

They're sending through stuff and I'm thinking—to do homework with Olly is a nightmare anyway, you have to get a volcanic crescendo for him to realise that 'mummy's not going to back down from this so I had better do it'. Which makes it emotionally wearing because then Daniel thinks I'm shouting at him, goes into meltdown so then I'm trying to maintain my position of power with one child and calm down the other child [who is] kicking the shit out of my walls [laughs]. So yeah. That's chaos [...] What I did in lockdown was I took things and if I could, I tweaked them. But they haven't asked for any of the work. (Donna, White British, autistic sons aged 15 and 13)

Many respondents' accounts revealed the amount of time and effort they put into sourcing materials, planning timetables and developing personalised approaches with which their children would engage.

For the young people, lockdown meant a stronger sense of security from being at home but also more isolation (Tokatly-Latzer et al., 2021). Several parents spoke of their children losing their social confidence with those outside of their immediate family. A chance meeting with a friend in the park distressed Rachel's daughter (aged 12), who later told her mother 'I can't remember how to talk to her'. Rachel reflected this 'was a little bit devastating because she struggles anyway with friendships'. Some stayed in touch with peers using messenger apps, although relationships with technology varied. Many struggled with anything as direct as Zoom, and therefore found it hard to talk to others. Gaming, however, provided

some with a vital social link through online communities. Nicole described her son as ‘angry, annoyed and lost’ over the lockdown. His online world, however, was another matter:

He is almost painfully shy in real life [...] Yet when we hear him on the game, he's chatty, he's witty, he's interactive, he's dynamic, he builds teams. It's quite phenomenal the difference in character. (Nicole, Black British, son aged 17)

Most of the children (apart from two) stayed at home during the first lockdown, influenced in some cases by the absence of key staff and the suspension of important provision, such as nurture rooms (rooms provided for small groups or individual work, often especially for SEN/D children). John had to challenge both his children's mainstream and special schools in order to get access for them to go to school, reminding them that government guidelines advised that children with EHCPs could attend. Those children who did attend school largely enjoyed the small groups and felt comfortable with the clear rules and routine implemented to ensure COVID safety, which also enhanced the predictability and transparency of school life and expectations. There was a similar reaction when the majority of children returned to school in September 2020. As Grace (White British, son aged 6) enthused: ‘*They have all got their own equipment with their name on—like rulers and stuff—which he loves.*’

CONCLUSION

The research advances important ‘lessons from lockdown’; chief among these is that families’ retreat into the private sphere of the home occasioned by the pandemic brought a sense of relief. This is no cause for celebration, however, as our analysis argues that this finding is revealing of the deep-seated stigma routinely attached to families with autistic children. The lockdown occasioned a means of stepping away from that stigma and offered them a temporary release from the ‘daily indignities’ (Link & Phelan, 2014, p. 30) of everyday school life described in the families’ pre-pandemic school experiences. The majority of our families had the economic, social and cultural capitals associated with the White British middle classes, which put them in a relatively advantaged position in terms of relationships with schools (Vincent, 2017). Nevertheless, our analysis illustrates a huge amount of parental labour required to support autistic children through and negotiate with (often inflexible and uncomprehending) systems of mainstream schooling. Lockdown occasioned additional points of tension as the lack of adaptation of school materials and the increased isolation from support networks acted as reminders of the families’ marginalisation, as stigmatised subjects. The disruptions in educational access and progression that they faced both during lockdown and in pre-pandemic times were understood to be *their* problems to solve, and not those of the institution in failing to accommodate them. Mullen (2015, p. 9) notes:

When our educational environments fail to meet the needs of autistic students, the autistic child is considered to be ‘in crisis’. The narrative of adaptation prevents us from reversing this interpretation and recognising the crisis of institutions themselves in accommodating diverse modes of mental processing, communication and behaviour that fall under the rubric of autism.

Developing Mullen's point further, we do not suggest that teachers deliberately stigmatise autistic children, although undoubtedly some stigma arises through variation in training and some negative or ill-informed attitudes towards autism among educational staff. Rather, we argue that stigma also operates through the often-embedded assumptions and expectations of the mainstream schooling system. Dominant conceptions about what it is to be, for example, a teenager

(what to like, what to be enthusiastic about, how to behave) and what it is to be a 'good' student, and how to manage one's time, work and relationships with staff and peers position many of the participant children as stigmatised subjects, since they are an awkward 'fit' with the normative expectations of mainstream schooling. Requiring 'reasonable adjustments'—even the small things that parents mentioned here—can be understood as a mark of deficiency in a system that emphasises individual self-responsibility and self-sufficiency. Many of the young people are understood within this set of assumptions as making active choices to respond as they do—and are therefore seen as sometimes wilful, defiant and/or aggressive.

Making adjustments for such young people, and departing from existing systems and expectations, is perceived as costly—in terms of teacher time, effort and resources. This speaks to the constraints of mainstream schools within the 'broader political economy' (Tyler & Slater, 2018, p. 732) in terms of funding and institutional in/flexibility, and the contemporary context of high-stakes accountability, which limits the agency of teachers to recognise and respond to these children's needs. In this context, some, but not all, of the children in our research may—with some adjustments—be able to meet their school's performative demands in terms of behaviour and/or attainment. However, many autistic young people do not reliably perform as productive individuals within the mould of mainstream schooling, and this is itself a source of stigma. Further research is needed on how we understand the workings of and relationship between individual, interactional and structural stigma in the contemporary neoliberal context (Thomas, 2021), that is between quotidian daily experiences of schooling for autistic children and their parents in our research and the workings of a political economy that devalues and marginalises autistic identities. Our contribution in this paper has been to argue that the pandemic casts a harsh light on the ordinary workings of symbolic power through mainstream schools, a power which creates and maintains 'spoiled identities' (Goffman, 1963) for many autistic students.

ACKNOWLEDGEMENTS

This paper develops our findings presented in the following report to BERA (Oliver et al., 2021): <https://www.bera.ac.uk/publication/the-experiences-of-autistic-young-people-theirparents-of-lockdown-the-reopening-of-schools>. As well as gratefully acknowledging BERA as funders of the research, we would also like to thank our research participants and advisory group members, and two anonymous referees for their helpful comments on earlier versions of this paper.

FUNDING INFORMATION

This research was funded by a grant from BERA as part of the Education and COVID-19 small grants fund.

CONFLICT OF INTEREST STATEMENT

No conflict of interest has arisen in this work.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ETHICS STATEMENT

The research was conducted in line with ethical guidelines outlined by BERA (2018) and ethical approval was granted from the Institute of Education, University College London at the outset (REC 1413).

ENDNOTES

- 1 <https://explore-education-statistics.service.gov.uk/find-statistics/special-educational-needs-in-england>.
- 2 The participants included a majority in professional occupations (e.g. teacher, researcher), but also two support workers. Parents self-described their occupations, but not always in sufficient detail to classify them accurately against National Statistics Socio-Economic Classification (NS-SEC) categories, which describe different middle-class groupings (i.e. 'higher' and 'lower' professional occupations). We do not have information on parental education.
- 3 These difficult experiences emerged in response to our open question: 'Can you tell us a little about X's experiences at school before lockdown?'

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How to cite this article: Vincent, C., Oliver, C., & Pavlopoulou, G. (2023). Lessons from lockdown: Autistic students, parents and mainstream schools. *British Educational Research Journal*, 00, 1–16. <https://doi.org/10.1002/berj.3854>